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Governor's Commission on Mental Retardation

TRANSPORTATION SERVICES FOR PEOPLE WITH MENTAL RETARDATION

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Report from the Commission's Public Hearing held
Tuesday, September 12, 1995 at Bristol Community College

TRANSPORTATION SERVICES FOR PEOPLE WITH MENTAL RETARDATION

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

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The Commission is especially grateful to Joanne Karger for her assistance in the development of this report. We also thank Larry Tummino, Assistant Deputy Commissioner, Department of Mental Retardation, for his assistance with the development of the historical overview.

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I. Introduction and Overview:

Mobility in our culture is an absolute must for all individuals. Jobs, recreation, and social opportunities, including volunteering cannot occur for people who are unable to reach out....Developmentally disabled persons need these opportunities in order to become part of their community. The lack of affordable public transportation in an area, or [not] knowing how to access public transportation are some of the obstacles developmentally disabled individuals face.

--Donna Kulpa, Families Organizing for Change

Transportation is one of the most challenging aspects of getting people jobs in the community because public transportation is not readily available....Further, employment opportunities are tied to people's transportation rather than the needs of the employee or employer.

--Pam Sampson, Alternatives Unlimited

The Department of Mental Retardation (DMR) funds transportation services for more than 8,000 persons. These services permit DMR eligible adults to attend day habilitation programs, sheltered work programs, and supported employment sites. Because many count on these transportation services to get to work, employment opportunities often depend on how well transportation runs--on its availability, reliability, and safety. Throughout the tenure of the Governor's Commission on Mental Retardation, concerns about transportation services have been expressed by providers, family members, and users of DMR funded services. Because transportation plays such a pivotal role in employment opportunities and because of the frequency with which concerns about transportation have been noted, the Governor's Commission on Mental Retardation held its fourth public hearing on transportation services.

The hearing was held on September 12, 1995 at Bristol County Community College in Fall River, MA. Seventy people attended the hearing. The keynote speaker was James McCormack, Executive Director of Seaside Education Associates, Inc., who discussed his agency's statewide study of transportation services. In addition to Mr. McCormack, 20 individuals testified. Five persons submitted written testimony.

This report highlights some of the challenges of providing transportation services to persons with diverse needs. The report is divided into three sections:

- a brief history of services and an overview of trends;
- a summary of the testimony;
- findings by the Commission.

A. Historical Overview:

Until the late 1970s, people with mental retardation living in the community had extremely limited access to day and work programs. For those who received services, transportation was provided by the local school system. Costs were minimal because participants were so few. As more people left the state institutions and moved into the community, local school systems were less willing to fund this rapidly expanding service need. Transportation costs were further complicated when state reimbursements for this service went to a town's general fund rather than to its school system. Several lawsuits were filed against towns who refused to provide transportation services. While none were successfully litigated, the suits resulted in a major change in the management of transportation services in 1982. The responsibility for transportation services now shifted from the local school system to the State Department of Education (DOE). By this time, nearly 5,000 people needed transportation, and costs averaged $19 million per year. A supplemental budget was required annually to pay for cost overruns. Quality was also a concern as DOE awarded transportation contracts solely on the basis of cost without regard for performance, management, or monitoring of the system. Stigma was also an issue with many adults with mental retardation riding to work on large "class 1" school busses.

In 1985, DMR took on the responsibility for the transportation of adults. Both the staff and management structure remained largely unchanged from the DOE system. The DMR transportation leadership increased additional emphasis on safety and reliability. Costs continued to escalate, climbing from $19 million to $32 million.

In 1989, the DMR faced dramatic cuts to its base budget, and the transportation budget was reduced by $6.5 million. Transportation providers were required to take a 5% decrease in reimbursement. Administration changes were no less dramatic: there was no longer a centralized transportation office. The regional DMR offices became responsible for contracting, bidding, and increasing the use of generic resources to allow as many consumers as possible to access transportation.

B. Trends:

Changing Role of Supported Employment Provider In order to control costs as well as to reduce the number of double and triple runs for persons receiving services, in July 1994 DMR created a new contracting option that enabled

supported and sheltered employment providers to also provide transportation to and from work. Some providers subcontract their transportation needs to transportation companies. Others now use direct service workers to transport their consumers whether in provider-leased vehicles or their personal cars.

Regional Transit Authorities One response to the budget crisis of 1989 was to increase collaboration with Regional Transit Authorities (RTAs). RTAs coordinate both the "demand response" and regular public transportation. Some training for citizens with disabilities on how to use public transportation is also available. Demand response ("The Ride" in the Metro Boston area) is for those individuals who need door-to-door service. With this service, the consumer might ride alone or with other persons with disabilities. Regular public transportation on fixed routes is fully integrated at the bus stop and on the bus. DMR has worked with local RTAs to make bus routes more flexible and accessible to consumers.

Efforts to increase the use of public transportation by persons with mental retardation have encountered resistance. Those who are accustomed to DMR door-to-door service especially worry about the safety of the consumers using public transportation.

Enhanced Collaboration A second initiative undertaken by DMR to cut costs and improve quality is an effort to promote inter-agency collaboration. The goal of this initiative is to work with other agencies, specifically the Division of Medical Assistance (DMA) and the Department of Public Health (DPH) to maximize the use of vehicles and drivers through a unified contract. *"The hope is that eventually most transportation companies can be subcontracted to transport people to a worksite, then using the same vehicle transport children to early intervention programs, then take Medicaid recipients to medical appointments, then return to do runs for transportation,"* commented Larry Tummino, Assistant Deputy Commissioner of DMR.

Changes in transportation services mirror the history of community inclusion for citizens with mental retardation. Beginning with extremely limited services, day programs for persons with mental retardation developed with a focus on providing specialized services segregated from persons without disabilities. As costs escalated and the importance of full community inclusion recognized, access to typical, integrated, "real work" settings have been emphasized. Transportation services have followed a similar pattern. Following an initial expansion of transportation which was costly and largely segregated, the focus is now on cost containment and an increase in the use of public transportation by capable adults with mental retardation.

II. A Summary of the Testimony:

A. Overall Satisfaction:

In his keynote address, Mr. McCormack noted that the results of his study reflected a positive response to transportation services among the recipients as well as their families. In fact, he said that the levels of satisfaction were *"Much higher than we have seen in any other type of DMR service."* Of the 315 recipients who participated in the study, 233 individuals, or 74%, indicated that they were either satisfied or very satisfied. Some of the aspects viewed as positive by participants and their families included: door-to-door service, the driver, and lack of a fee for the service. Mr. McCormack also noted that, in addition to the recipients and their families, 90% of the day program staff found the transportation services to be either satisfactory or very satisfactory.

Other hearing participants also expressed satisfaction with transportation services. For example, George Mavridis, the President of Coalition of Families and Advocates for the Retarded (COFAR), noted that transportation services for individuals with mental retardation in Massachusetts are running very well: *"Transportation services at Dever, Fernald, Glavin, Hogan, Monson, Templeton and Wrentham are the best in recent memory....Transportation services for retarded people in Massachusetts follows a sine curve. Today it is at the apex of the sine curve...."* Similarly, in her written testimony, Lucie Chansky of Newton, noted that for the most part transportation services have been well received. She wrote, *"For the majority of individuals with mental retardation the current transportation system is appropriate."*

B. Concerns:

1. Duration of Travel One problematic issue noted by Mr. McCormack was that some trips of relatively short distances required very lengthy travel times. Although many of the participants in the study lived within two miles of their worksite, the average travel time was 41 minutes. Moreover, most of the people who used DMR funded transportation had to change vehicles at least once. Mr. McCormack gave several examples of individuals who traveled long routes: *"This young man starts in Carver. He goes to Plymouth where he sits for a while at one workshop. A van picks him up and then transports him up to Marshfield where he sits at another workshop for a while; where a third van picks him up and takes him over to Rockland where he actually has his job...He spends a good deal of time traveling....This [other]...fellow lives in Newton. He's transported down to*

Dedham. He then...gets on a van and goes back to Newton where his job is, probably about three miles from his house. Then in the afternoon he gets on a van, goes back to Dedham, then gets off that van and gets on another van and goes back to Newton about two miles from his house. We do this quite often."

Several speakers at the hearing noted that the length of the trips does not diminish overall satisfaction. Mr. McCormack explained, *"Our conclusions were that if you get a service that is door-to-door...it's going to be rated high even if there are some things happening along the way."* Similarly, John Long, Executive Director of SCM Community Transportation stated, *"I think you'll find that satisfaction of service is not solely dependent on the length of the trip."* Another reason why family members may be willing to have their loved one travel for such lengths of time is that the six hour program at a day habilitation center or other segregated setting is typically too short for a person with mental retardation who cannot be left at home alone. *"That happens a lot, and we've had this kind of perverse system where people have used transportation as a means to cover time for people because they don't have that relief or the coverage, particularly with two family members working,"* states Mr. Tummino.

2. Stigmatization Several speakers commented on the fact that transportation for persons with mental retardation is often segregated and stigmatized. Mr. McCormack stated, *"Regional transportation vehicles are typically marked in some manner identifying they're special. For example, on the ride out here we saw a van with four young men in it. It said 'handicap' in big nice letters on the top; 'school bus,' 'license plate,' 'students.' Let's keep the eternal child alive. So the ride is very segregated."* Larry Tummino, on the other hand, said that many of the vehicles which DMR uses today are vans, and that most do not have signs written on the outside. He stated, *"Most of those vans...do not have lettering."*

Another problem with the segregated transportation system is the excessive use of the horn. The Seaside report noted that *"Drivers honked the horn upon arrival at an individual's home and when dropping them (sic) off in the afternoon for 90 participants. This practice affected 75 participants who traveled on vehicles funded by the Regional Transportation Offices. 15 of provider transported participants also were subjected to this procedure."* During the hearing, Mr. McCormack told the following: *"...one man who lived in Hadley....didn't have any staff. When he went home, they would always blow the horn, and he told the driver, 'I live by myself. There are no staff at home to come out. I don't need this.'*

The next day, the driver blows the horn. He blows the horn every time. Some of the people said that they thought this was insulting to them, and the neighbors asked sometime, 'Why when you come home do people blow the horn?' I think he tried to explain it in some type of musical chairs. But he did not like it."

3. Safety Another issue raised was that of safety. In his testimony which centered on the DMR-owned vehicles used by those who live in facilities and community-based, state-operated programs, George Mavridis noted that in the past, Massachusetts had allowed the vehicles transporting people with mental retardation to deteriorate, and consequently every five or six years they failed the registry's annual inspection and could not be driven. He said that COFAR believes that preventative maintenance must be regularly scheduled on DMR vehicles, and that money has to be allocated to replace old or defective vehicles. He feels that these two factors are crucial in allowing the DMR transportation service to achieve the goal of community inclusion. Similarly, Lucie Chansky noted that she feels that penalties should be given for inadequate service as well as for vehicles that are in poor condition, and that the vehicles have to be evaluated regularly. Jim McCormack reported that, in his study, *"Direct observation of each Department funded vehicle utilized by participants indicated that none of the vehicles had any detectable faulty equipment. Interviews with drivers and transportation provider personnel indicated that repairs and maintenance of the vehicles were completed in a timely fashion and that vehicles were reported as being maintained in safe condition at all times....Drivers from both Regional Transportation Office funded vehicles and provider vehicles reported that the equipment identified above was typically present."*

In addition to issues related to the vehicles themselves, safety issues pertaining to the driver of the vehicle were noted. Barry Schwartz, Senior Vice President, Vinfen Corporation, mentioned some of the qualifications which Vinfen requires for its drivers in order to ensure safety. For example, the drivers must be at least 21 years old and have a valid driver's license, with no more than two moving violations within the last three years, and no convictions for driving recklessly or driving under the influence of alcohol. Nor can they have had their licenses revoked or suspended for any reason during the past three years. Mr. Schwartz also noted that all of the staff at Vinfen are required to enroll in a two and a half week training program, which includes first-aid, CPR, and crisis prevention training as well as human rights training. In addition, all of the staff members receive two days of training in the administration of medication.

4. Provider and Worker Liability Concerns about liability were expressed during the public hearing. Several people mentioned the liability issues that occur when members of the staff transport persons with mental retardation. For example, Pam Sampson of Alternatives Limited stated, *"We are very fortunate because we have a very dedicated staff who are willing to use their own vehicles to transport people despite of what the liability might be."* Joel Smith, Executive Director of Autism Services Association (ASA) in Wellesley also said, *"The issue again that has been talked about before [is] about personal vehicle use for business purposes and the increased insurance premium. Also the increase in workmen's comp rates going from human service category to transportation category. There are personal liability issues."*

Bonita Keefe-Layden, Executive Director of South Central Rehabilitative Resources, said that one of the major issues surrounding transportation is workers' compensation. She also noted that her agency must carry umbrella liability policies. Similarly, Barry Schwartz commented that as Vinfen has downsized many programs, direct care staff are more involved with transportation. Consequently, he recommended *"that this Commission deal with liability issues for direct care staff and umbrella policies that help insulate our direct care staff."*

John Rose of the Irwin Siegel Agency, Inc., noted an additional issue related to liability--the liability involved with transporting individuals who use wheelchairs. He stated, *"When we talk about transportation liability, I'm also reminded about another issue that needs resolution, like people who use wheelchairs and manufacturers and transportation providers are at odds on how to transport. Who is liable for wheelchair users' safety?"*

C. Trends:

1. Increased Reliance on Public Transportation Although recipients of DMR transportation services are satisfied with the services provided, many of the presenters expressed the view that the ultimate goal is to encourage individuals with mental retardation to use public transportation. Donna Kulpa, a member of Families Organizing for Change, stated, *"I would like to see the developmentally disabled traveling side-by-side with the rest of the public. Friendships that are formed in commuter situations are worth it."* She also noted, however, that although she felt that it is important for individuals with mental retardation to use public

transportation, they often face barriers such as a lack of affordable public transportation, or a lack of understanding as to how to use public transportation. In addition, Ms. Kulpa mentioned that there are high costs involved in training individuals with disabilities to take public transportation.

Similarly, Lucie Chansky stated in her written testimony, *"Whenever possible, an effort should be made for DMR consumers to learn to use public transportation or car pools with co-workers. The money invested to train will be costly at first but will eventually be very cost effective."* She went on to say, *"Long term, all work and day program providers should be located near public transportation routes, and individuals should live as close as possible to their work programs, without sacrificing the need to live in appropriate settings."*

Significantly, Mr. McCormack explained that Seaside's study showed that many participants were capable of taking public transportation. For example, 131 of the participants could walk by themselves for at least two miles. 66 of the people used public transportation on evenings and week-ends. 79 people used taxi cabs and 55 could do all three. Furthermore, 66% of the participants had access to public transportation, meaning that within 2 miles of these individuals' homes there was some type of public transportation such as a bus stop or a train stop.

Other hearing participants acknowledged the presence of obstacles in using public transportation. Bob Hebda noted that they have about 100-130 people who use public transportation daily, and about 150 people who still use transportation provided by DMR. *"Most people that have taken the public transportation have vowed they would never go back to DMR because they don't have to put up with long rides, crammed vehicles, drivers that are rude, or whatever else comes up....There are, or course, risks and consequences that people incur when they get into a vehicle like this...of people being asked for money or falling down because of their disability."* Mr. Hebda suggested that it is often easier to train people who are just turning 22 to use public transportation than to get people who have been using DMR transportation for some time to change. Moreover, in Fall River, it is easier for individuals to take public transportation than in other parts of the state because bus routes run every half hour. Fall River also uses "travel trainers" to help train individuals to take the bus and actually to go down to the bus terminals and help them deal with the various problems.

Bonita Keefe-Layden also discussed the issue of public transportation. She noted that her company daily transports up to 500 individuals with disabilities. She mentioned several problems with public transportation in her area. For example, she said that in Western Massachusetts there is not enough public transportation reaching all of the towns in the area.

Ms. Keefe-Layden also said that there needs to be sufficient demand to warrant the use of public transportation. She explained, *"Public transportation generally provides transportation on fixed routes and requires a certain level of customer activity to be cost effective for it to justify even having a route. People with developmental disabilities do not all live on a route, and their needs are not met by a fixed-route situation for public transportation."* Ms. Keefe-Layden also mentioned that individuals with disabilities need transportation for activities other than their day programs; for example, recreational and respite activities. In addition, she said that the individuals often have physical as well as developmental disabilities. Moreover, some cannot be trained to take public transportation. Public transportation is appropriate for people who can be travel-trained, however, she stated that most persons with developmental disabilities are not capable of this especially if they need to transfer from one vehicle to another. Ms. Keefe-Layden also suggested that *"the elderly population and the general public feel very threatened and uncomfortable sharing their services with individuals who have developmental disabilities. They're not comfortable dealing with aggression, self-abuse, incontinence, or seizure activity."*

My name is Jim Newberry. I live in Lawrence and work in Northampton, Massachusetts.

I want to let you know that we sure need transportation at night to go places and also on Sundays or holidays, especially in the bad weather months when it gets icy and slippery and all that, there's a lot of spots where a person has to walk at night where it's pitch dark, and there is no light, and they can't see the ice, and a person ends up falling and getting seriously hurt, which happened to me a few times when I used to work evenings back in the mid '80s.

We also need transportation on Sundays and holidays to get to and from church and other places like that.

There are a lot of those streets in Northampton that are dangerous trying to cross. Cars won't stop when they see a pedestrian waiting to cross. They just speed right by.

Something has got to be done about this matter. We need more transportation to get places, especially at night or on the weekends.

--Jim Newberry, Self-Advocate

2. Employment Specialists Providing Transportation Mr. Tummino described the DMR's emphasis on transportation by supported employment providers: *"First of all we felt like if the supported employment provider had control over those dollars, they would make better use of them, cut down on some of the double and triple rides where the sheltered workshop was being used as a transfer point much like a big bus station. People come in and wait for the next bus to get onto it to get to their supported work site. It doesn't make sense. So we tried as much as we could during this last bidding period to build more of our funding right into the base of the supported funding provider.* Joel Smith said that two years ago DMR contracted with ASA to provide its own transportation services. Today, much of the transportation is being conducted by the job coaches in their own vehicles. He noted the following advantages to the current system: greater control; flexibility to design and change routes; improved capability of dealing with new referrals and of bringing the consumers directly to their employment sites; incentive for staff to increase their income; lower cost than contracted transportation; and fewer behavioral problems and other difficulties along the routes because the job coaches, who know the consumers well, are driving.

We had...two consumers who lived in West Roxbury. They would be transported to our center in Wellesley. They would change their clothes, go to the bathroom, and then our job coaches would transport them back to West Roxbury to the Star Market. They would work there. Then we would transport them back to Wellesley. They would change their clothes, go to the bathroom, pick them up in the afternoon and drive them back to their residences in West Roxbury.

Since two years ago, we now provide transportation for most of our clients. Those two particular clients and others we now pick up directly from their residence and drive directly to their worksite without going to the Wellesley center. We'd like to see that increase.

--Joel Smith, Autism Services Association

Smith also mentioned a number of disadvantages with the day programs providing transportation: the difficulty with residential staff having consumers ready for travel on time; the unwillingness of the residence to tell ASA when the consumer is not home; difficulties when a regular ASA staff member is not available to drive.

In his written testimony, John M. Foster of DMR-Region I, noted that *"Smaller and mid-sized programs, particularly those located away from public transportation routes, are finding that the transportation funds...are insufficient and the alternative transportation options are few. In the past, transportation providers had the cost effectiveness of scale. For example, by running full vans...to various programs, sufficient funds would be available to cover general operating expenses. Now, with individual programs accepting the responsibility for transporting their own program participants, the economic base is not only comparatively smaller but the operating costs are larger. Rurally-based programs are especially affected as not only do participants have to be transported over great distances, but program staff are using more of their work week driving, leaving less for program services."* He notes, however, that these difficulties can be resolved by fundamentally changing the way transportation is funded--*"Rather than funding 'runs,' we should fund people...For example, one rurally-based agency which serves people living scattered over a large area has tried hiring staff people close to where program participants live, allowing staff people to then "car pool" with those participants. Use of PVTA mobility training has been increased, and it will not be long before everyone who is able will be using public transportation. Contract arrangements with taxi services have shown mixed success. Car pooling with neighbors who work the same hours and who work in the same community seems to work when the person with the disability is living in a family home."*

III. Findings:

Members and staff of the Governor's Commission on Mental Retardation were heartened to find that overall satisfaction with transportation services is high. To learn this through a major independent study from Seaside Educational Associates, Inc., as well as through supportive comments from members of COFAR and the SAC reduces some of the concern which prompted the hearing on transportation. The Commission also applauds the spirit of innovation that the DMR, providers, and others have brought to the field. Marty Krauss, Chair of the Commission, noted at the conclusion of the hearing that, *"It is interesting how adversity often breeds opportunity. Budget cuts always sound like horrible things, and they usually are. But many of those who spoke today illustrated how, when they had to rethink how they were going to provide services for less money, they often came up with ways that made the services better or served a lot more consumers."* The Commission supports DMR's efforts to promote collaboration both in the use of RTA's and inter-agency collaboration with Medicaid and DPH. Supports such as the travel trainers, transit station monitors in the Fall River area, and the increased use of carpools in rural areas are the kinds of innovations which the Commission is pleased to encounter.

Although overall satisfaction with transportation services is high, and transportation services appear to be generally safe, concerns have also emerged. These concerns include:

- the long length of trips to and from work;
- the on-going pattern of double and triple runs to get to a worksite;
- the lack of use of public transportation by citizens with mental retardation who are currently able to use public transportation;
- the persistent concern of providers who have encountered changes in their liability and workers' comp obligations as they begin to take on the responsibility of transportation;
- the burden of extra auto insurance costs on direct service workers who can ill afford such an expense at a reimbursement rate of .22 per mile;
- the use of transportation service as a form of "respite," that is, as a way to extend the typical six hour day of programming to accommodate the needs of family members and residential providers.

Jim McCormack noted at the conclusion of his testimony, *"I am not sure that just trying to change transportation is really going to make a difference. What I believe is really going to make a difference is looking at day services. Transportation is like the image in a mirror. You can't change the image in the mirror. What you have to do is change the image that's being reflected and the image that's being reflected is day services."* It is evident from this hearing, discussions with family members and providers, as well as site visits to day programs that day services and transportation are indeed closely linked. Both types of services are undergoing significant changes, with DMR working to provide more substantive "real work" experiences for its citizens. Cost containment and reliance on utilization of generic resources for transportation have been the chief items on DMR's transportation agenda. As these services evolve, the Commission hopes that accommodations designed to increased the use of public transportation by citizens with mental retardation will be expanded, including the availability of travel trainers throughout the Commonwealth and monitors at peak times in urban transit sites, timing bus routes to coincide with the hours of a work program, and situating work programs in proximity to public transportation. The Commission hopes that within the near future all citizens who have the capacity to use public transportation will be doing so. The Commission fully recognizes that not all citizens will be able to use public transportation. Those who live in the rural areas of the Commonwealth will need to network to find rides to and from work. Those citizens who will continue to require specialized transportation for whatever reason, should have the right to services of the highest quality--transportation with trained drivers in safe vehicles for reasonable lengths of time.